

Good Death—Bad Death: Quality of Care at End of Life

William L. Barrett

Department of Radiation Oncology, University of Cincinnati College of Medicine, Cincinnati, OH, USA

Address correspondence to William L. Barrett (William.Barrett@uc.edu)

Received: May 18, 2020; Accepted: June 15, 2020

Barrett, W. Good death—bad death: quality of care at end of life. *Glob J Qual Saf Healthc.* 2020; 3:87–88. DOI: 10.36401/JQSH-20-18.

© Innovative Healthcare Institute

Is there any such thing as a good death? Certainly, there are many, many bad deaths. What would a good death be? Surrounded by family in comfort and dignity after a long, full, productive life with few regrets? What aspects of the “quality” of death can be influenced by caregivers? Generally, not the patient’s age or their life’s accomplishments or their longstanding relationships with family and friends. Yet, the particular circumstances around a patient’s final days are obviously very important to them and are indelibly etched in the memories of their loved ones. Those memories will be important in the long term and the caregivers can be influential. The primary responsibility of the medical professional is to assure the comfort and dignity of the patient.

How do you let someone know they are dying?^[1] Should you let them know early in their disease course that their death is inevitable? Should you discuss it only when there is no hope? Should you let the patient come to the conclusion on their own? Is your discussion with the patient the same as your discussion with the family? Part of the reason for the grayness is that we are all, in effect, dying. We purposely and/or involuntarily specifically do not focus on this fact. Being consumed with our inevitable death could significantly impair our ability to live life. How is it different for someone with a terminal disease?

Denial is a relative term. Some people near the end appear to be in denial, as they are not thinking so much about death as they are about living. Is that all bad? Are we not all, in some respect, in denial about our mortality? Do we not look forward to tomorrow, ignoring the eventuality of our death, which could certainly be tomorrow, but we manage to assume will be many years from now? “Live every day to the fullest, live every day as if it is your last.” These are popular expressions, but how many of us could live today to our fullest if we believed we were going to die tomorrow? A few maybe, but would most people not be consumed with fear and depression? Fear of the unknown. Afterlife? Believing that may help.

Depression over leaving the people, places, and things we know and love.

Everyone is different. By nature, some people want to know as accurately as can be predicted their longevity; some do not. The medical caregiver’s obligation is to be respectful of each individual and to try to tailor the approach to them, based on the patient’s approach, with some general guidelines, including:

1. Be relatively honest.^[2] You cannot be 100% honest because you do not know. Miracles occasionally happen and unforeseen events frequently happen. If someone has clearly incurable disease, they can be told, but how they are told is very important. The role of the medical caregiver is not to completely close the door on hope. If a patient gives up hope, that should be on their timeframe and at their discretion. I know a patient who took an Alaskan cruise and attentively listened to lectures about Alaskan wildlife days before he died from a relentless cancer. Everyone around him knew his prognosis was days to weeks. He refused to look at it in those terms and looked forward to tomorrow to the very end. Denial? Was that all-bad? He was not uninformed. He was a physician who knew that he had widely metastatic disease. A medical caregiver could certainly have sat him down weeks before and emphasized his prognosis. How would he have responded? I think he would have fired the caregiver, become depressed (which he was not), and foregone the trip. Does the elephant in the room have to be addressed? Sometimes yes and sometimes no. A gray answer? It is an inherently gray topic and nothing is going to change that. If a patient is declining and needs supportive care (i.e., hospice) but will not accept help without their prognosis being discussed, then it needs to be discussed. The situation of someone declining without appropriate support can be associated with unnecessary pain and suffering at home alone or with family that needs help they are not getting with an eventual 911 call, trip to the emergency room, resuscitation, and placement on a ventilator leaving the family with the difficult decision of removing life support or continuing fruitless, uncomfortable care in the intensive care

unit. Specifically, how do you tell someone their prognosis in a way that is accurately informative without inducing panic and completely removing hope? My suggestion is as follows:

“Mr. X, if someone has a cancer that appears to be localized, often there is the possibility of getting completely rid of it and being cured with surgical removal or with radiation therapy or with radiation and systemic therapy. If someone has disease that has spread to several places, there may not be the chance to get completely rid of it, but there may be treatment that can cause the disease to regress and stay regressed for some period of time. Sometimes that regression is for a short period of time; sometimes for a long period of time. There are a few diseases that can be cured with systemic therapy, even when wide spread. With no treatment, the disease is likely to progress, but how quickly is quite unpredictable. Even with no treatment, your immune system is fighting the disease and may keep it in check even long term. With or without treatment, eventually the cancer is likely to progress and let us take one step at a time. If a particular symptom or problem arises, we can address it. Nothing about this should be painful with the medicines and treatments that are available. Like everything in life, you hope for the best but prepare for the worst.”

How to introduce hospice.^[3]

“Do you need more help at home? If so, there are home visiting nurses that can be of help or the group that has particular experience in being helpful to people with cancer is hospice. Hospice is a group of nurses and social workers that can visit as often as necessary and can be very helpful. If you need certain equipment, such as a hospital bed or a walker, they can get it for you quickly and save a lot of hassles and you do not get charged for it. Same if you need a new medicine—they can go get it for you quickly with no hassles or charge. Most hospice care is home hospice where they visit you. There is inpatient hospice if necessary but that is not what we are talking about right now. People often do not like the sound of hospice and for someone to be enrolled in hospice they are supposed to have a life expectancy of 6 months or less but nobody ever really knows, and people will sometimes get hospice help for a while and then check back out of hospice. If you would be potentially interested, we could have someone from hospice stop by your house just to explain to you what they can offer and you can decide if you want their help or not. If not, that is no problem but it would not hurt to at least meet them, if you would be interested.”

2. Be available. Promise patients that you will be available to them throughout their illness and mean

it. Be available to their family members as well. Having discussions with the patient and family members together is best so everyone is on the same page. The one question that family members frequently have out of earshot of the patient is “how long do you really think he or she has?” I generally answer that nobody ever knows with certainty but my guess is $_$, which may be several days, weeks, or months depending upon the situation. Family members frequently need to know this to decide whether to have out of town family visit now or a month from now. The best death for an individual may be a sudden death after a long productive life. Death after a chronic disease, such as cancer, is probably more difficult than sudden death for the individual. Death associated with a chronic disease can potentially afford the individual and the family members time to solidify relationships and close gaps. The word goodbye may not be spoken but the sentiment expressed. The medical caregiver can have a very positive influence in removing anxiety from the patient and the family’s concern about a painful, suffering death and can provide reassurance to the patient about the courage they have shown in fighting their disease and the pride they should have in their accomplishments and particularly in their family.

The Kübler-Ross stages of grief^[4] in terminal illness of denial, anger, bargaining, depression, and acceptance are in our experience variable in occurrence, order, and duration but can sometimes inform the patient and family experience for the medical caregivers.

The most important component is for the healthcare provider is to maintain an attitude of availability, compassion, and dedication to guiding the patient and family through a most important phase with priorities of enhancing comfort and dignity.

References

1. Back A, Friedman T, Abraham J. Palliative care skills and new resources for oncology practices: meeting the palliative care needs of patients with cancer and their families. *Am Soc Clin Oncol Educ Book*. 2020;40:1–9.
2. MacKenzie AR, Lasota M. Bringing life to death: the need for honest, compassionate, and effective end-of-life conversations. *Am Soc Clin Oncol Educ Book*. 2020;40:1–9.
3. Johnson K. ‘A good and peaceful death’: cancer hospice in the pandemic. 2020 Medscape. <https://www.medscape.com/viewarticle/931819>. Accessed June 05, 2020.
4. Curry LC, Stone JG. The grief process: a preparation for death. *Clin Nurse Spec*. 1991;5:17–22.